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U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

JUN 01 2015

VIA FIRST CLASS MAIL

The Honorable Earl Ray Tomblin
Governor
State of West Virginia
Office of the Governor
State Capitol
1900 Kanawha Boulevard, East
Charleston, West Virginia 25305

Re: United States' Investigation of the West Virginia Children's Mental Health System Pursuant to the Americans with Disabilities Act

Dear Governor Tomblin:

We write to report the findings of our investigation of West Virginia's system of care for children¹ in need of mental health services. We find that the State does not comply with Title II of the Americans with Disabilities Act of 1990 ("ADA"),² 42 U.S.C. §§12131-12134 (2006), as interpreted in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), requiring that individuals with disabilities, including children with mental illness, receive supports and services in the most integrated setting appropriate to their needs.

This letter describes the violations and notifies the State of the steps it should take to meet its obligations under the law, as required by the ADA and Title VI of the Civil Rights Act of 1964, 42 U.S.C. §2000d-1 (2006). By implementing the remedies set forth in this letter, the State will correct identified ADA deficiencies, fulfill its commitment to individuals with disabilities, and better utilize State resources.

We thank State officials for their cooperation and assistance throughout our investigation. We appreciate that the State facilitated meetings with officials and the medical staff at Sharpe Hospital. We also appreciate the walk-through tour of the West Virginia Children's Home. We

¹ For the purposes of this letter, children are defined as people under the age of twenty-one.

² Pub. L. No. 101-336, 104 Stat. 337.

hope to continue our collaborative and productive relationship as we work toward an amicable resolution of this matter.

I. SUMMARY OF FINDINGS AND CONCLUSIONS

We conclude that West Virginia fails to provide services to children with significant mental health conditions in the most integrated settings appropriate to their needs in violation of the ADA. The State has needlessly segregated thousands of children far from family and other people important in their lives. With adequate services, the State could successfully treat these children in their homes and communities. The systemic failure to develop critical in-home and community-based mental health services also places children with mental health conditions who currently live in the community at risk of unnecessary institutionalization.

Our specific findings include:

- Children who depend on the Department of Health and Human Resources (“DHHR”) for mental health services experience high rates of placement in segregated residential treatment facilities,³ including out-of-state placement, because DHHR has not developed a sufficient array of in-home and community-based services. Unnecessary placement in segregated residential treatment facilities, and removal from their families and communities, can harm children. Children frequently lose the ability to make everyday decisions about their lives because facilities regiment all daily activities. The harms of unnecessary placement can also include the use of seclusion, and chemical and manual restraint by facility staff members. Children unnecessarily segregated into these residential treatment facilities frequently engage in additional disruptive behaviors, leading to further segregation and isolation from their communities.
- Children who live in the community and need, but do not receive in-home and community-based services, are at risk of unnecessary placement in segregated residential treatment facilities. Certain children with mental health conditions are at heightened risk: status offenders; lesbian, gay, bisexual, transgender, and questioning children; trauma-exposed children; children with both mental health and intellectual disabilities; minority children; older children; and previously placed children.
- West Virginia has not fully implemented its *Olmstead* plan. It has not developed comprehensive, community-based services for children with mental illness, including wraparound supports that are the standard of care for children with

³ “Segregated residential treatment facilities” referred to in this letter include Group Residential Care, Psychiatric Residential Treatment Facilities, and psychiatric hospitals. DHHR defines Group Residential Care to include structured 24-hour group care settings for children with needs that range from adjustment difficulties in school, home, and/or community to those in need of highly structured programs with formalized behavioral programs and therapeutic interventions. See Bureau of Children and Families, W. Va. Dep’t of Health and Human Res., Terminology, http://www.wvdhhr.org/bcf/documents/management/dataReports/FCPlacements_Detail.pdf.

- significant mental health needs. West Virginia has not developed statewide community-based crisis services, nor has it effectively diverted children from unnecessary placement in segregated residential treatment facilities.
- West Virginia has taken insufficient steps to reallocate existing resources for mental health services to, and has not taken full advantage of Medicaid support for, in-home and community-based services. Medicaid funding is the foundation for integrated services for children in numerous other jurisdictions, but West Virginia has failed to recalibrate its medical assistance program to ensure the provision of in-home and community-based care.
- Child-serving agencies in West Virginia fail to collaborate to address the needs of children with mental health conditions involved in multiple systems. As a result, agencies duplicate efforts, waste limited state resources, and provide fractured care delivery, causing confusion and harm to children and families.
- West Virginia fails to engage families effectively to develop strategies to support children in their homes and communities. Families perceive their interactions with DHHR as more punitive than supportive, undermining the potential to develop strengths in the home and keep children in the community.
- West Virginia continues to fund expensive placement in segregated residential treatment facilities both within the state and out of state, but neglects to develop sufficient community-based services. National data and local providers report that the cost of providing in-home and community-based mental health services ranges from \$2,500-\$3,500 per month. By contrast, the average cost of in-state placement in segregated residential treatment facilities ranges from \$5,623 to \$9,088 per month. In addition, out-of-state placements cost West Virginia over \$20 million in fiscal year 2012.

The unnecessary segregation of children with mental health conditions violates their civil rights and wastes the State's fiscal resources. Community integration with core services and supports will permit the State to support children in their homes and in their communities in a lawful, effective and cost-efficient manner.

II. INVESTIGATION

On April 29, 2014, we notified you that we were initiating an ADA investigation of West Virginia's programs for children with mental health conditions. We visited the state four times (June 2-3, July 28-August 1, September 22-24, and November 3, 2014) to assess the system of care for children with mental health conditions. Accompanied by our expert consultant, we visited children's mental health service providers, advocates, children, and families across the State, from the most rural and poverty-affected areas to urban centers. We toured nine in-state segregated residential treatment facilities and two shelters housing children with disabilities. We also traveled to two neighboring states to tour segregated residential treatment facilities where

West Virginia places significant numbers of its children with mental health conditions. The ADA violations detailed in this letter exist throughout the West Virginia children's mental health system.

In addition to interviewing and touring, we reviewed a wide range of documents about the children's mental health system. The reviewed documents included those sent to us by West Virginia in response to an information request. We also reviewed publicly available information including statewide plans, reports, and state policies.

III. BACKGROUND

The focus of our investigation in West Virginia was on the services available through the Department of Health and Human Resources ("DHHR") to children with mental health conditions. These children enter the public mental health system through several avenues including the child welfare system, the juvenile justice system, and the medical assistance program ("Medicaid"). Regardless of the point of entry, these children have significant mental health needs that are largely unmet in the community. On December 1, 2014, there were 1,017 children with mental health conditions residing in segregated residential treatment facilities – 25% of all children in DHHR custody. This rate of institutionalization is well above the national average of 15%.

Children come into DHHR's custody either through the abuse and neglect system or through juvenile justice proceedings. Courts place children into DHHR custody when they are removed from their family homes in response to abuse or neglect allegations. DHHR generally sends those children to segregated residential treatment facilities when they have significant mental health needs. In addition, courts have discretion to place adjudicated status offenders and low-level delinquency offenders either in the juvenile justice system or in DHHR's custody. Some of the children in segregated residential placements are juvenile justice-involved youth placed in DHHR's custody by the courts.

DHHR's custody, while often intended as an alternative to the juvenile justice system, can also become a gateway to that system. If status and low-level delinquency offenders fail in a DHHR placement, the court may place the child in a juvenile justice facility. In addition, children in the child welfare system with mental health conditions, who were not previously juvenile justice-involved, sometimes move from failed treatment into juvenile justice proceedings. One common path for transfers is when children living in segregated residential treatment facilities engage in behavior such as resisting restraints, pushing staff, or similar acts. The State frequently charges these children with delinquency and transfers them to the juvenile justice system.

Another gateway to the juvenile justice system for children with mental health conditions involves children who initially remain in the community in a deferred prosecution status known under state law as an "improvement period" or "pre-adjudicatory community supervision." Although the improvement period is intended to serve the rehabilitative needs of the child, the State often fails to provide needed services to children with disabilities during this time. Without necessary services, these children may continue to engage in behaviors that violate the

requirements set by the court. They may even re-offend because of their unaddressed disabilities. Children who cannot satisfy the terms of the improvement period are then adjudicated in the juvenile justice system. The courts can then place these children in juvenile justice facilities where mental health treatment is limited. During the most recent legislative session, S.B. 393 became law, requiring referral to community services “intended to reduce delinquency and future court involvement.” S.B. 393, 2015 Leg. (W. Va. 2015). This change is consistent with our recommendations, but does not specifically require the provision of mental health services to children who need them.

Not all children with mental health needs who rely on DHHR’s mental health services are in DHHR custody. Low-income children also rely on DHHR’s Medicaid program for needed mental health care. Because there is little access to mental health services in the community through Medicaid, many children with mental illness in West Virginia either are at serious risk of unnecessary segregation or have been unnecessarily institutionalized. Children on Medicaid often cannot get sufficient services to support them in their homes and communities. Several providers admitted to us that they provide little or no community services to children in their catchment areas. Even residential services in-state are limited; most in-state beds are filled with court ordered placements. Without access to intensive services, Medicaid eligible children have no alternative but out-of-state placements. West Virginia authorized placement of 346 Medicaid children in out-of-state segregated residential treatment facilities between July 1, 2011 and June 30, 2012, isolating those children from their homes and communities both by the segregated nature of the programs and by their geographic distance from home.

IV. FINDINGS AND CONCLUSIONS

A. West Virginia Over-Relies on Segregated Residential Facilities and Continues to Build More Segregated Programs

“The system is built up around residential treatment facilities.”

-- Public Defender

Our investigation found that West Virginia has built its entire children’s mental health system, including child welfare and juvenile justice, around placement in segregated residential treatment facilities. This over reliance on segregated residential facilities when they are inappropriate for children’s needs violates the ADA. “In passing the ADA, Congress explicitly identified unjustified segregation of persons with disabilities as a form of discrimination.” *Olmstead*, 527 U.S. at 600. The Court in *Olmstead* held that community-based services should be offered when (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (c) community-based services can be reasonably accommodated taking into account the resources available to the entity and the needs of others who are receiving disability services from the entity. *Id.* at 607.

Indeed, in recent years West Virginia has deepened its reliance on segregated residential treatment. DHHR has authorized providers to build new residential programs and expand existing bed capacity in segregated programs across the state. These include new psychiatric hospital wards targeted to children and adolescents in Charleston, Clarksburg, and Wheeling, and

a new 24-bed segregated residential treatment program for children adjacent to an existing children's in-patient psychiatric facility. Recently, six facilities added residential services for children in DHHR's custody with an acute psychiatric diagnosis. In addition, DHHR's WV Child Placement Network website reflects substantially increased residential capacity in the last year and a half – from 1,085 beds in May 2013 to 1,163 in December 2014. There is little evidence to suggest that DHHR has reduced its commitment to segregated residential treatment programs.

During our investigation, we visited twelve residential treatment programs. All were segregated settings. The facilities varied from large campus-based programs holding hundreds of children with mental health conditions, to smaller programs housing 10-12 children. These facilities all had strikingly similar elements reflecting pervasive segregation of children with mental illnesses. Each facility was limited to children with mental health conditions, severely limiting contact with non-disabled peers. Most facilities required children to finish a standardized points-based system to complete the program. Each facility, which is both the children's treatment facility and their "home," required participation in highly regimented activities for every aspect of the children's lives, without any right to refuse the activity or exercise independent judgment. Many of the programs we visited had an on-ground school. At these programs, the children took classes only with other residents of the segregated residential treatment facility, and sometimes the school was in the same building in which the children lived.

West Virginia reports that its child welfare system has a higher percentage of youth in segregated residential treatment facilities than 46 other states. In its application for a Title IV-E Waiver ("IV-E Waiver") from the Administration for Children and Families, West Virginia reported that DHHR placed 71 percent of children between ages 12 and 17 in its custody into segregated residential treatment facilities.

West Virginia children enter segregated residential care primarily through the juvenile justice system and the child welfare system. Both systems rely on a Multidisciplinary Team for making placement recommendations to the court. DHHR is required to convene the Multidisciplinary Team in three circumstances: child abuse and neglect cases, adjudicated status offense cases where the court is considering placement into DHHR custody, and adjudicated delinquency cases where the court is considering placement into DHHR custody. West Virginia law describes the Multidisciplinary Team process as "a system for evaluation of and coordinated service delivery for children who may be victims of abuse or neglect and children undergoing certain status offense and delinquency proceedings." W.Va. Code §49-5D-1(a) (2014). The Multidisciplinary Team approach has potential to divert children toward needed in-home and community-based services and away from unnecessary segregated residential treatment. The Multidisciplinary Team is required to review assessments of children and make recommendations to the court. Advocates informed us that, once the team makes its recommendation, it is usually accepted by the court.

In practice, the Multidisciplinary Teams often fail to consider or recommend the mental health services needed to avoid removal from the home. Instead, the Mutidisciplinary Teams routinely recommend segregated residential treatment. The process does not effectively facilitate

the delivery of mental health care to children in the most integrated setting. Advocates and families reported that the most influential team participants are the Juvenile Probation Officer and DHHR staff assigned to the case. According to them, these team members drive the consistent recommendations for segregated residential treatment placement.

The propensity of Multidisciplinary Teams to recommend segregation undermines their potential to ensure that the State serves children in the most integrated setting appropriate to their needs. During our meetings across the state, multiple stakeholders reported that the Multidisciplinary Team process largely fails to consider in-home and community-based services. One advocate described the Multidisciplinary Team meetings as “Short and sweet. It lasts 15 minutes. [Everyone is] watching the clock. They walk through the requirements.” According to one West Virginia public defender, the Multidisciplinary Team recommends placement based on which segregated residential treatment facility has a bed. Similarly, a probation officer informed us that the Multidisciplinary Team determines the least restrictive placement solely in the context of out-of-home placements; in-home and community-based services are not even considered.

In juvenile justice cases, courts have the option under state law to defer adjudication for any child facing charges for a period of up to one year, known as an “improvement period.” According to West Virginia statute, the court may impose terms and “conditions calculated to serve the rehabilitative needs of the juvenile.” W. Va. Code §49-5-9. In practice, conditions are not individualized to each child’s rehabilitative needs. The improvement period terms are often standardized and typically require that children attend school every day, not disrupt the educational process, and not violate any rules of the school or their parents. For children with mental health conditions, these terms may be unattainable without services and supports. The West Virginia Rules of Juvenile Procedure allow the court to direct DHHR to provide services and treatment for the child and family, and DHHR is required to make “reasonable efforts” to prevent an out-of-home placement. Yet court personnel and attorneys reported that the courts have few service options in the community and that DHHR does not provide sufficient services necessary to enable a child with a disability to comply with the terms of an improvement period order.

A just-announced collaboration between the United States Attorney’s Office, the West Virginia State Police, DHHR, and the West Virginia Center for Children’s Justice, promises to work for expanded prevention and intervention services for children involved in abuse and neglect proceedings. We applaud this initiative, which is consistent with our recommendation that the State allocate resources to develop these critically needed community services. In addition, newly-enacted HB 2550 takes steps to stem the tide of children pulled into the juvenile justice system through truancy proceedings. This is an important step and consistent with our recommendations and, together with the increased community-based services called for by the ADA and these findings, promises to improve outcomes for children with mental health disabilities. However, in the absence of the community services called for by the ADA, these reforms may not reach many of the children who could benefit from them most.

In addition to juvenile justice and child welfare-ordered placements, parents who depend on Medicaid are often forced to place their children in out-of-state facilities because sufficient in-state services are not offered. The West Virginia State Medicaid Plan includes coverage for

institutional mental health care in Psychiatric Residential Treatment Facilities, but there is only a handful of in-state beds for children who are not court involved. These children are not able to access in-state residential treatment or sufficient in-home and community-based services to successfully remain in their own homes, or even in their own state.

For children with significant mental health conditions, the default service in West Virginia is institutionalization. At critical junctures, including when a court needs to identify if the child has a mental illness, or when a residential treatment setting does not have a bed available, the State places children in highly restrictive settings. During our tours, we learned that DHHR did not routinely provide diagnostic evaluations to children facing charges, so courts sent them to a juvenile detention center for mental health diagnostic evaluations if they suspected the child may have a mental health condition. While a new state law will require these evaluations to be completed within 30 days, the evaluations can currently take months to complete. A more accurate, less expensive and more thorough evaluation could be performed for most children in their homes and in the community, rather than in the most highly restrictive setting available - a secure detention center. Prior to a change in 1997, the State had routinely performed these diagnostic assessments in the community. DHHR also holds children in emergency shelters when the chosen placement for a child does not have a space. The child can wait for months at a time in the shelter. There they often do not receive the intensive mental health treatment needed to address their mental health needs and avoid institutionalization. Holding children in shelters is a consequence of the State's dependence on residential treatment.

B. West Virginia Fails to Provide In-home and Community-based Mental Health Services to Children Who Need Them

"Parents are forced to send their kids to out-of-home care to get them the services they need."

-- West Virginia Parent

DHHR provides intensive mental health services to children almost exclusively in segregated residential treatment facilities. Yet these children are qualified for community placement. Under the ADA, a "qualified individual with a disability" is an "individual with a disability who, with or without reasonable modifications...meets the essential eligibility requirements for the receipt of services." Nondiscrimination on the Basis of Disability in State & Local Gov't Servs., 28 C.F.R. § 35.104 (2010). States are required to provide community-based treatment for qualified persons with mental health conditions where such treatment is appropriate. *See Olmstead*, 527 U.S. at 601-02. The appropriateness of community treatment can be shown through evidence that people with similar needs are receiving services in integrated settings with appropriate supports.⁴

Marshall University conducted a study of West Virginia children who received in-home and community-based services funded by a federal grant. The study concluded that the State had successfully served those children at home, even though many of them had multiple mental

⁴ Statement of the Dept. of Justice on the Enforcement of the Integration Mandate at Question 4.

health diagnoses and had been previously hospitalized. *See Decreasing the Cost of Mental Health Services and Improving Outcomes through a System of Care*, Marshall University, February 2006. West Virginia's experience with reduced institutionalization and increased cost effectiveness is similar to that of numerous other jurisdictions across the country that have developed community-based systems of care. *See Return on Investment in Systems of Care for Children with Behavioral Health Challenges*, National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development, February 2015.

Other states successfully support children with similar mental health conditions in their homes and communities. We compared the clinical profiles from West Virginia to children served in states that have developed statewide in-home and community-based services. The children we reviewed in West Virginia presented similar diagnoses, treatment needs, life histories, and treatment histories to children in other states who receive in-home and community-based mental health services.

1. Community-based Services Are Effective for Children with Significant Mental Health Needs

“Services such as prevention and early intervention, accessible community-based mental health and substance abuse treatment, therapeutic foster care, and respite services are seen as key factors in preventing youth residential placement.”

-- Carrie W. Rishel, et al., *Preventing the Residential Placement of Young Children: A Multidisciplinary Investigation of Challenges and Opportunities in a Rural State*, 37 W. Va. Univ. Child & Youth Servs. Rev. 1, 9-14 (2014).

“In WV, we do not have a true treatment foster care system as defined by the Foster Family Treatment Association (FFTAA). True treatment foster care and wrap-around are essential to meet children’s needs.”

-- Speaker, *Community Forum*.

In-home and community-based services effectively support children with mental health conditions and can reduce reliance on segregated residential treatment. These services generally fall into four categories: Intensive Care Coordination, Crisis Response and Stabilization Services, Direct Services available in the child’s home or community, and Therapeutic Foster Care. Studies have shown that intensive community-based services of this nature effectively address the needs of children with mental illness while maintaining their connection to their families and communities. Programs across the country, including those in Wisconsin, Maine, New Jersey, and California have greatly reduced the rate of institutionalization and related costs while producing positive outcomes for children. Children with comparable levels of need who receive intensive services in their natural settings have improved school attendance and performance, increased behavioral and emotional strengths, improved clinical and functional outcomes, reduced suicide attempts, and decreased contacts with law enforcement when compared to children who received such care in segregated residential treatment facilities. Other benefits include reduced costs of care, more stable living situations, and improved attendance at work for caregivers.

Intensive Care Coordination (also known as wraparound) includes assessment and service planning, accessing and arranging for services, and coordinating multiple services, including access to crisis services. Assisting the child and family to meet basic needs, advocating for the child and family, and monitoring progress are also included. Many children with significant mental health needs are involved in multiple systems, such as child welfare, mental health, juvenile justice, and special education. Intensive Care Coordination brings together services that address children's mental health conditions across these systems. A single, consistent care coordinator facilitates assessments, care planning, coordination and monitoring of direct services, such as therapeutic mentoring, respite, functional behavioral assessments, and in-home individual and family counseling. In lieu of wraparound, an Assertive Community Treatment team can provide these services for older youth between the ages of 18-21.

Crisis Response and Stabilization Services can be planned interventions for a child already receiving services, but can also be an entry point for newly connecting a child to community-based mental health services. These services, such as mobile crisis services, are accessible every day, all day, to provide an effective non-law enforcement alternative that responds when a child experiences a mental health crisis.

Direct services provided in the home and community help the child build the skills needed to live successfully in the community and the family's ability to support the child at home. Providers of these services engage children in activities that are integrated into the community and where they learn skills needed to function independently in a natural setting. Direct services include educating and training the child's family about the child's condition, in-home assessments, behavioral support, individual and family therapy, and therapeutic mentoring.

Therapeutic Foster Care is a community-based, cost effective alternative to segregated residential treatment facilities for children with significant mental health needs who are unable to remain in their family homes. It provides safe and nurturing care to a child in a more structured home environment than typical foster care. Therapeutic Foster Care is an intensive, individualized mental health service provided in a family setting, using specially trained and intensively supervised foster parents.

As discussed more fully below, West Virginia offers variations of these services to limited populations in a few areas of the state. Expansion of these services would benefit West Virginia children.

2. Collaboration Is Necessary to Support Children in Their Most Integrated Setting

“Had every agency that was involved communicated with each other I believe he could have worked through this instead of being placed.”

-- West Virginia Parent

States that have successfully developed integrated mental health services have done so by fostering engagement of families and community members as full partners in developing

strategies to support children in their homes and communities. Beth A. Stroul & Robert M. Friedman, *Effective Strategies for Expanding the System of Care Approach: A Report on the Study of Strategies for Expanding Systems of Care*. National Evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program (2011). Children in West Virginia who have been in segregated residential facilities report that they want to more fully participate in the decisions that affect their lives. One youth stated:

“Treat us like humans instead of criminals. Don’t isolate us. Have positive, caring people working as staff... Interact more so we don’t feel like caged animals. More simple rights.”

DHHR has long recognized the significant need for and lack of child and family outreach and engagement. Families report that they do not feel welcomed, supported and heard by service agency staff. Family participation can improve the way DHHR serves children and adults by increasing the focus on families, on providing services in natural settings, and on cultural sensitivity. Collaboration with schools and other naturally existing community supports, including faith communities, civic organizations, and the business community, is also essential to an effective community-based system of care.

During our tours across West Virginia, we heard from many stakeholders that families perceive DHHR staff members as a threat to the integrity of the family. A mother of a 14-year-old boy with a significant mental health condition and intellectual disability reported that she would “like it if DHHR wouldn’t threaten to take my kids away or make me feel I have done something wrong.” Another parent said that DHHR would take the child away if the parent were unable to visit him due to work demands, cost, or transportation issues once DHHR places the child out of state. In West Virginia, many parents report that the State did not treat them as a partner in the treatment decision-making process.

3. Programmatic Barriers Prevent Institutionalized Children from Accessing Integrated Services

Question: “Tell me what you need to accomplish to be discharged?”

Answer: “Ain’t really tell me, if I have to complete the program and get all levels, there’s 6 to get out, don’t know.”

-- Interview of Child in Out-of-state Placement, *Regional Clinical Review Team Report*.

West Virginia’s children in segregated residential treatment facilities are required to complete arbitrary requirements that slow the child’s transition back to the community. Our interviews with children and their families, our review of the State’s Regional Clinical Review Team reports, and our tours and interviews with service providers revealed that institutional barriers prevent discharge to the community. These barriers include requirements by the facilities that are unrelated to furthering the child’s ability to achieve mental health stability in a community setting.

Every staff member we interviewed at these segregated residential treatment facilities stated that children had to complete a rigid program that usually required graduating through

several behavioral levels. Graduating up the levels required children to complete specific tasks or demonstrate desired behavior. In some programs, the time spent on each level is rigid; even if the youth displays the behavior prior to the facility's set time on each level, the youth still remains on that level. For instance, at one segregated residential treatment facility, a director told us that a child must remain on Level 1 for 2 weeks and achieve 85% compliance with the behavior expectations before moving to Level 2. Levels 2 through 4 require youth to remain on the level for 28 days with 85% compliance before progressing to the next level. The facility does not tie the requirements to the child's individual treatment needs, especially to needs related to family relationships or the ability to navigate in everyday school and social settings in their home communities.

This type of rigidity was found across the spectrum of segregated residential treatment facilities. At one out-of-state facility we visited, every child had to complete the same standardized goals: 1) accept negative criticism, 2) follow instructions, and 3) accept "No" for an answer. At one facility, we observed teenage girls working toward meeting their behavioral levels by walking together in a single file line and reciting a blessing before entering the dining hall. These behavioral requirements do not teach the child the skills needed to be successful in family relationships and remain stable in the community. Furthermore, for a child with both intellectual disabilities and a mental health condition, these goals can be very difficult to achieve due to the combined effect of their disabilities.

West Virginia children with mental health conditions placed in restrictive settings remain in those settings for reasons unrelated to their individual mental health conditions. From program site visits and the review of Regional Clinical Review Team recommendations, we identified numerous examples of lengths of stay tied to program requirements (e.g., completing the program's level system, finishing the "semester" or a pre-set program component) and not to the child's treatment needs. Segregated residential treatment facility providers we interviewed stated that children spend up to a year in their facilities. West Virginia's System of Care initiative reported that children with mental health conditions placed in out-of-state segregated residential treatment facilities spend an average of 253 days (over 8 months) in the facility. The longest placement was 1,365 days (3 years, 9 months). This prolonged institutionalization is partly the result of regimented, non-individualized requirements that create programmatic barriers to discharge.

4. West Virginia's Failure to Provide Essential Integrated Community Services Keeps Children Unnecessarily Institutionalized

The lack of in-home and community-based services prevents children with mental health conditions from receiving services in an integrated setting. The State has acknowledged this fact. In its 2005 Strategic Plan to reduce its dependence on out-of-state placement, the State acknowledged a need to implement some of the community-based services essential to prevent unnecessary institutionalization, including in-home and community-based crisis response services and community stabilization to prevent unnecessary hospitalization. West Virginia's plan also required officials to review the availability of alternatives to segregated residential treatment facilities, such as foster homes, step down programs, and outpatient services. Where

necessary, the State pledged to increase funding and change policy in order to increase services. In the 10 years since it released this plan, however, the State has yet to implement consistent, statewide in-home and community-based services to prevent unnecessary institutionalization of children with mental health conditions.

The lack of in-home and community-based mental health services results in court ordered placements into segregated residential treatment facilities for infractions as minor as truancy. One juvenile court judge reported that placement is a last resort, but if a child continues not to attend school, then he looks to treatment. He reasons that a child will get what he or she needs in the facility because they have mental health treatment there. This same judge stated that he would order more home confinement if there were mental health services locally.

Children with mental health conditions are routinely sent into a segregated residential treatment facility to receive critically needed care. For example, the clinical reviewer who assessed Keith⁵ for placement after he was adjudicated delinquent discussed the option that Keith could “return home with increased therapy time with his previous therapist, consistent medication management, and in-home support services.” He noted that placement in a psychiatric residential treatment facility “may cause an increase in [Keith’s] aggressive behavior because of being forced into social situations with difficult peers and constant authority figures.” The Regional Clinical Review Team instead chose to recommend placement at a segregated residential treatment facility without any explanation for why it rejected the community-based option.

For children placed out-of-home, the lack of in-home and community-based services results in longer stays in segregated residential treatment facilities. An out-of-state provider said that West Virginia children stay in the provider’s facility two months longer than youth from the provider’s own state. Because of the lack of in-home and community-based services in West Virginia, many of these children are discharged to yet another segregated residential treatment facility. In contrast, children from the state where the facility is located leave the program sooner and return home with in-home and community-based services.

C. West Virginia’s Failure to Provide Integrated Services Places Children in the Community at Risk of Unnecessary Institutionalization

“Help doesn’t kick in until it’s really bad – very deep end or breaking the law.”
-- State Official

The lack of in-home and community-based mental health services available to children in West Virginia means that children with significant mental health conditions who live in the community without sufficient mental health services are at risk of institutional placement. DHHR is responsible for providing Medicaid eligible children sufficient mental health services in the community to avoid unnecessary institutionalization. In West Virginia, Medicaid provides health care coverage to approximately half of the children in the state – with an estimated

⁵ The names of children referenced in this letter have been changed to protect their privacy.

186,189 children receiving Medicaid services at any given point in time. The Annie E. Casey Foundation estimates that 20% of children in West Virginia – or roughly 37,240 children with Medicaid coverage – have one or more emotional, behavioral, or developmental conditions. National prevalence data indicates that approximately 8 percent of all children have mental health conditions so serious as to significantly interfere with their functioning in family, school, or community activities. For West Virginia’s Medicaid program, this amounts to an estimated 14,900 children.

Intensive services in the community in West Virginia are limited and insufficient to meet the needs of children at risk of institutionalization. Individual behavioral health counseling was the most frequently authorized therapeutic service. Yet in 2013, children receiving this counseling got an average of only 60.5 hours per year - approximately one hour-long therapy session per week. For many children, this level of intensity is insufficient to prevent unnecessary placement in a segregated residential treatment facility. DHHR identifies four services as “Intensive Service Program” services that can be authorized at higher intensity for a limited period. However, few children receive these intensive services.

The protections of the *Olmstead* decision extend to children at risk of institutionalization and segregation, and are not limited to those individuals who are currently in institutional or other segregated settings. *Pashby v. Delia*, 709 F.3d 307, 321-22 (4th Cir. 2013). In fact, a state’s failure to provide community services may create a risk of institutionalization. *Id.* at 322; *see Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1182 (10th Cir. 2003) (“failure to provide Medicaid services in a community-based setting may constitute a form of discrimination”); *see also Radaszewski v. Maram*, 383 F.3d 599, 609 (7th Cir. 2004) (“a State may violate Title II when it refuses to provide an existing benefit to a disabled person that would enable that individual to live in a more community integrated setting”); *Peter B. v. Sanford*, No. 6:10-767-JMC-BHH, 2010 WL 5912259, at *6 (D.S.C. Nov. 24, 2010) (“a State’s failure to provide services to a qualified person in a community-based setting as opposed to a nursing home or institution presents a violation of Title II of the ADA”). The at-risk population in West Virginia includes those children who live in the community but who have under-treated mental health conditions that place them at serious risk of institutionalization.

Families across the state report that their children cannot access mental health care in the community because the State does not inform them how or where to access services; there are not enough services or qualified staff available; or services are not available unless the child is in DHHR custody. Predictable consequences of under-treated mental health conditions – acting out behaviors, problems at school, sexualized behaviors, and threats to self or others – become the primary issues that lead to placement. Parents report that their children could have remained in the home if they had been able to access needed mental health services in their community, if services had been available earlier, if they had access to qualified professionals, and if care had been better coordinated.

One child at risk for placement is Michael, a 9-year-old boy living with his mother in a small town. This child has intellectual disabilities, autism, and depressive disorder. He resisted a classroom aid who improperly restrained him and was charged with delinquency. The court found that Michael was too young for the State to place in a segregated residential treatment

facility, but indicated that if he were 11 or 12, it would consider such a placement. The court recognized that the community system had not provided sufficient services and ordered an improvement period. This was Michael's first interaction with the juvenile justice system, but without sufficient in-home and community-based mental health services, it will likely not be his last.

The children we reviewed have severe and complex mental health conditions. Most have multiple diagnoses, including major depression, post traumatic stress disorder, bipolar disorder, attention deficit/hyperactivity disorder, sometimes with co-occurring intellectual disabilities and eating disorders. A number of the children appeared to pose treatment dilemmas for the professionals working with them. Many of the children have serious and persistent behavioral issues that would require a behavior plan and in-home behavioral assistance to implement the plan consistently, to coordinate with other providers, and to teach the child and family how to respond to behavior problems in the context of their daily lives. Without such services, many of these children may not be able to remain at home, succeed at school, or avoid institutional placement.

Certain groups of children in West Virginia are at heightened risk for placement in segregated residential treatment facilities due to the lack of community-based services:

Status Offenders: Children with mental health conditions who are status offenders (i.e., truant) make up a large portion of children placed by DHHR in segregated residential treatment facilities. Three quarters of the juvenile justice-involved children placed in these facilities by DHHR in 2012 were status offenders, half of whom had no prior contact with the court.

LGBTQ youth: During site visits and interviews, providers and advocates reported the lack of services to support children with mental health conditions who identify as Lesbian, Gay, Bi-Sexual, Transgender, or Questioning. They also reported examples of serious bullying by their peers and a lack of understanding and protection from professionals who are responsible for keeping them safe and providing needed treatment services. DHHR does not have LGBTQ-specific protocols or policies for mental health care providers.

Trauma Exposed Children: Children who have been exposed to trauma typically become less resilient and more vulnerable to future trauma. Children in West Virginia face traumatic experiences at higher rates when compared with other youth in the nation. The State's data shows about 19% of children in West Virginia have experienced abuse or neglect, nearly double the nationwide rate of just over 10%.

Dually Diagnosed Children: Children who have been diagnosed with both intellectual disabilities and mental illness are at increased risk for placement in segregated residential treatment facilities far from home. Twenty-two percent of children placed in out-of-state facilities had both a mental illness diagnosis and an intellectual disability.

Minority Children: Children from racial minority groups, particularly African American children, are disproportionately represented in West Virginia's public mental health system, and thus have a greater risk of placement in a segregated residential placement facility. African American children with serious emotional disturbances represent 9.4% of those served in publicly funded programs, nearly triple their 3.4% representation in the state. As a whole, all minorities (African American, Hispanic, multi-racial, Asian, Native American, and "other") represent 20.5% of children served by publicly funded programs, more than triple their 6.1% representation in the State. African American students represent 5% of students with disabilities in the State during the 2009-2010 school year, yet they represented 9% of the students with disabilities referred to law enforcement, and 19% of the students with disabilities involved in school related arrests.⁶

Previously Placed Children: Children previously placed in a segregated residential treatment facility are more at risk of subsequent placement. Out of 510 youth in out-of-state placements, 120 youth had been out-of-state at least twice in the last 5 years (24%). 15% of youth placed by DHHR in out-of-state facilities had been unsuccessfully placed before within the state. In one study, 72% of children who returned from out-of-state placements to West Virginia re-entered the system.

Older Children: The State is more likely to place older children in segregated residential treatment facilities. West Virginia's fiscal year 2013 data shows that 3,263 children ages 0 through 17 came into DHHR custody through the child welfare system. Of the 1,488 children 12-17 years of age, 71% were placed in congregate care. Even those over the age of eighteen are at risk of placement. In fiscal year 2012, the State placed 37 youth who were age 18 or older in out-of-state facilities. The risk of institutionalization facing older children increases after they turn 18 years of age as the availability of services changes to reflect the adult services array. In fiscal year 2013, West Virginia Medicaid approved 208 youth ages 18-21 for placement in a psychiatric hospital.

These higher risk populations will be an area of continued inquiry and focus. The heightened risk of institutionalization of children in some of these categories suggests that there are potential Equal Protection issues in the delivery of mental health services. We have made no findings as to the State's compliance with the Fourteenth Amendment. Nonetheless, the State should develop and track the data necessary to meet the needs of these specific populations and ensure that it does not discriminate.

⁶ Available at: http://ocrdata.ed.gov/StateNationalEstimations/Projections_2009_10. The 2009-2010 school year is the most recent year that the Office for Civil Rights published statewide estimations.

D. West Virginians Desire Increased Community-based Mental Health Services

“I am sick of not having options.”

-- Juvenile Court Judge

The State’s 2006-2007 System of Care initiative survey of stakeholders concluded that the “overall deficiency of least restrictive, community-based services and supports trumps all other barriers” to the provision of a community-based system of care approach. The State’s efforts since this study was issued have not significantly reduced the number of children unnecessarily placed in segregated residential treatment facilities.

Children, their parents, and the courts want alternatives to segregated residential treatment facilities. Throughout the state, the families with whom we spoke tried to access community-based mental health treatment and faced significant barriers. They reported experiencing long waits for minimal services. For instance, we interviewed Johnny, a 17-year old youth with a mental health condition and his mother. Johnny and his family sought treatment at the Comprehensive Center, the safety net provider under state law,⁷ and could not get needed services. Their challenges to finding treatment have included long waiting lists for appointments, and once they received an appointment, the inability to receive consistent, intensive mental health supports. Because of the inability to receive community services, Johnny had been in psychiatric hospitals 16 times and in 2 segregated residential treatment facilities.

Unnecessary confinement in a segregated residential treatment facility “severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” *See Olmstead*, 527 U.S. at 601. Jane and her mother have struggled to find the services that Jane needs. These services were lacking in the community. As a result, Jane spent seven months in a segregated residential treatment facility in another state. Jane’s experience was distressing: in addition to being over four hours away from her family, she reported that she had to sleep on air mattresses on the floor and had to take cold showers every day. After this experience, she began to have severe anxiety and panic attacks. Johnny’s and Jane’s families, and all of the families we met, said that they would welcome community treatment options.

At meetings we held across West Virginia, state officials, community leaders, advocates, parents, and children all decried the lack of in-home and community-based services. DHHR representatives acknowledged the need to expand and better coordinate community-based services. The judge who told us that he was “sick of not having options” other than segregated residential treatment as a disposition reportedly struggles to find mental health agencies that will provide needed mental health services. Similarly, the public defenders with whom we spoke also noted frustration at the lack of community-based mental health treatment options in the state. They told us that when a judge gives a child a deferred prosecution and refers him to mental

⁷ Comprehensive Centers are a system of community mental health and intellectual disabilities centers that are required to provide for the treatment needs of persons with mental health or intellectual disabilities. W. Va. Code § 27-2A-1(b).

health treatment, there is a three-month waiting period to get an appointment. Often the child will re-offend while waiting for mental health treatment. Public defenders also reported that it is difficult to find private psychologists in their communities. The benefits of getting good mental health treatment are tremendous, according to these lawyers. They note that judges are much more willing to work with a child with a minor re-offense if the child is receiving services.

E. West Virginia Can Realign and Expand Services to Accommodate Children in the Community

“We are way too bed driven – especially on a Friday. It’s not about a good match, but where there’s a bed. That’s the focus.”

-- West Virginia Provider

1. West Virginia Has Failed to Implement its Olmstead Plan or Expand Successful Pilot Projects and Initiatives to Serve All Children

West Virginia has identified many of the services necessary to support children in their most integrated setting, as required by federal law. However, West Virginia never implemented the mental health services and supports for children that it contemplated in its 2005 Olmstead Plan. An Olmstead Plan is a comprehensive and effective plan to integrate individuals with disabilities into the community. *See Olmstead*, 527 U.S. at 584. In its most recent Annual Report reflecting implementation of the Olmstead Plan, West Virginia reported no activity for children’s services, including no progress on “the development of comprehensive community-based services for people in recovery from mental illness including wraparound supports,” for children called for in the 2005 Plan.

Outside of the Olmstead Plan process, the State has developed numerous studies, reports, and pilot programs that have examined various aspects of service delivery for children with significant mental health needs. These reports detail the problems associated with depending on placement in segregated residential treatment facilities: costliness, lack of accountability, and poor program services. Many of these reports focus on the budgetary impact of out-of-state placements. However, the State has failed to use these reports to develop a comprehensive, cross-system plan to address high levels of unnecessary institutionalization of West Virginia’s children in segregated residential treatment facilities.

West Virginia has undertaken a series of promising initiatives to address some part of the gap in community-based mental health services. While often pilot projects and grant-based initiatives, the community has learned much from these prior and on-going efforts. Although these initiatives are disjointed, serve limited populations, and have limited funding, some of these initiatives provide a strong base for achieving *Olmstead* compliance. The budding School-Based Mental Health Initiative, operated as a pilot program, has shown promise and good outcomes in those schools that have the grant. Project Intercept is a grant-funded initiative that has diverted many children in Kanawha County from juvenile justice involvement by providing case management services, individual therapy, and family therapy. The recently approved IV-E Waiver Application will eventually allow the State to redirect federal child welfare funds currently used for children in out-of-home placements to in-home services in an effort to avoid

removal. West Virginia has also recently implemented a network of Youth Service Centers that will improve access to services for children with a substance abuse disorder, including those with a co-occurring mental health condition. In addition, West Virginia's Medicaid State Plan includes community-based services that can be expanded to become the building blocks for in-home and community-based services. These include Basic Living Skills Development, Targeted Case Management, and Assertive Community Treatment.

However, pilot programs, small initiatives or programs targeted at sub-groups of the Medicaid population do not adequately ensure that all children who rely on DHHR for mental health care are not unnecessarily placed in segregated residential treatment facilities. They fall far short of the comprehensive statewide plan needed to address children's mental health needs and related ADA compliance issues.

Development and implementation of a comprehensive action plan for in-home and community-based mental health services would further compliance with West Virginia's obligations under both federal and state law to provide mental health services to children in their most integrated setting.

2. The State Can Afford to Provide In-Home and Community-Based Mental Health Services

The State's over reliance on segregated residential treatment facilities drains state resources that could be used to fund the development of in-home and community-based mental health services. During the State's fiscal year 2012, DHHR spent over \$67.5 million dollars on in-state and out-of-state residential placements. The State spent most of that money (\$47.2 million) on residential placements within West Virginia.

The State's overreliance also has cost implications for the State's education system. For each child in out-of-state placement, the child's home county school district must pay the cost of special education services provided to that child. Of the \$6 million that the State allocates to county school districts for special education services, over \$2.2 million is spent to pay for education services provided to youth in out-of-state placements. This greatly affects some counties; in Berkeley, Hampshire, Morgan, and Ohio counties, the cost of special education services for children placed in segregated residential treatment facilities exceeds their entire yearly state special education allotment.

The average monthly cost of DHHR's placements in segregated residential treatment centers within the state ranges from \$8,106 to \$9,088. As noted above, many children spend months in children's emergency shelter facilities while they wait for beds to open up, and there the costs are even higher: from \$9,661 to \$10,835 per month. In contrast, the average cost for in-home and community-based services for children in states with established programs is approximately \$3,500 per month. West Virginia providers report that they could maintain many children in the community at a cost of \$2,500-\$3,500 per month.

West Virginia can draw from its own experience with savings by looking to the now-defunct Mountain State Family Alliance previously funded by SAMHSA in Region II (Boone,

Cabell, Clay, Jackson, Kanawha, Lincoln, Logan, Mason, Mingo, Putnam, Roane, and Wayne counties). Mountain State Family Alliance provided in-home and community-based mental health services, including coordination, technical assistance, and facilitation of Multidisciplinary Team meetings, intensive care coordination, flexible services and funding for non-traditional mental health services, respite care, and parent-to-parent information and support. A 2006 study conducted by Marshall University into the cost savings of that program found that:

After the children were in the study for six months, overall there was a 13% decrease from six months prior to System of Care enrollment. After they were enrolled for one year, overall there was a 32% decrease in cost for six months prior to enrollment. After they were enrolled for one and a half years, there was a 63% decrease in cost from six months prior to enrollment.

DHHR's own assessment of this program found it reduced costly utilization of hospital and residential placements – children with high rates of prior segregation in hospitals or residential treatment programs were now all successfully supported in their homes and communities. Johnny reported that he received intensive care coordination and mentoring from Mountain State Family Alliance and was able to live successfully in his home until the grant ended, when he was in fourth grade. After that point, he deteriorated and began his journey through multiple residential placements – including 16 separate stays at in-state private psychiatric hospitals, two stints in a segregated day program for full terms of 16 weeks each, and an out-of-state placement over a thousand miles from home. The family felt that if the Mountain State Family Alliance had continued, they could have avoided years of separation and trauma. In addition, the State could have significantly reduced the cost of providing mental health services to this child if it had continued with its community-based wraparound services.

West Virginia already has a duty to serve children covered by Medicaid under the Early, Periodic Screening, Diagnostic and Treatment Services (“EPSDT”) provisions of the Act, 42 U.S.C. § 1396d(a)(4)(B) and 71.35% of the cost of these services can be reimbursed to the state. EPSDT requires that state Medicaid programs provide children under the age of 21 with any services coverable under the Medicaid Act necessary to correct or ameliorate a mental illness or condition, regardless of whether that service is included in their State Plan. 42 U.S.C. § 1396d(r)(5). The EPSDT obligation is broad, requiring West Virginia as a Medicaid participant to provide comprehensive health care services, including in-home and community-based mental health treatment. *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 52-53 (D. Mass. 2006) (“[T]he EPSDT provisions of the Medicaid statute require, by their very language, comprehensive assessments of children with SED [serious emotional disturbance] ...the EPSDT provisions of the Medicaid statute require provision of adequate in-home behavioral support services for SED children”); *see also, Katie A. v. L.A. Cnty*, 481 F.3d 1150, 1159-60 (9th Cir. 2007) (agreeing that states have an obligation under the EPSDT mandate to provide effective in-home behavioral support services to children with mental illness, but overturning the lower court’s requirement that the services be bundled); Centers for Medicaid and Medicare Services & Substance Abuse and Mental Health Services Administration, *Joint CMS and SAMHSA Informational Bulletin: Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions* (May 7, 2013).

West Virginia's Medicaid program includes some in-home and community-based services, including Targeted Case Management for children with mental health conditions under specified circumstances. In addition, West Virginia's Medicaid State Plan covers Basic Living Skills Development, Community Psychiatric Supportive Treatment, Assertive Community Treatment and Crisis Intervention services. However, providers, families, advocates, and court personnel all report that many children who need these services cannot access them. Nonetheless, West Virginia remains obligated under Medicaid to provide State Plan services to support children in the community.

Other states provide for a wider array of Medicaid covered in-home and community-based services to successfully support children with mental health conditions in their homes and communities. For example, Massachusetts supports children with intensive in-home services designed to reduce symptoms, ensure crisis response and support, link the child and family to community resources, and prevent out-of-home placement. The fact that West Virginia is already obligated under EPSDT to provide the services children need provides further support for the realignment of resources and the expansion of community services.

3. West Virginia Law Supports Community-based Cross-System Mental Health Services

West Virginia law and policy support the provision of mental health services in the least restrictive setting for children. The West Virginia child welfare statute governs both child welfare and juvenile justice placements. An overarching legislative goal of both programs is to “provide services that are community-based, in the least restrictive settings that are consonant with the needs and potentials of the child and his or her family.” W. Va. Code § 49-1-1(a)(7). In the juvenile justice system, the state statute calls for an “individualized program of rehabilitation [that] shall take into account the programs and services to be provided by other public or private agencies or personnel which are available in the community to deal with the circumstances of the particular juvenile.” W. Va. Code § 49-5B-4(b). The statute directs DHHR and the Division of Juvenile Services to establish “[c]ommunity-based programs and services to work with parents and other family members to maintain and strengthen the family unit so that the juvenile may be retained in his or her home.” W. Va. Code § 49-5B-4(a)(2). However, the State has not implemented these provisions sufficiently to produce the array of in-home and community-based services needed to prevent unnecessary institutionalization.

The value of cross-system coordination reflected in the West Virginia statute has not actually resulted in coordination between child-serving agencies sufficient to support children in their most integrated setting. For example, families, court personnel and legal advocates have told us that, in the juvenile justice context, children are “set up to fail” because the standardized conditions for the improvement period are not tailored to the individual needs of the child. DHHR reportedly does not provide the assistance these children on the brink of juvenile system involvement need to be successful. Children with significant mental health conditions are often unable to meet the demands imposed by the terms of the court during the improvement period and are sent out-of-home, to either segregated residential treatment facilities or to Division of Juvenile Services facilities. Many children have been placed in segregated residential treatment

facilities after failing to comply with court-ordered counseling because they could not access community-based mental health services through DHHR's network of providers.

In spite of these operational shortcomings, the goals of both programs and statutory requirements is to develop cross-system, community-based services for children. The way to realize these statutory goals is by developing intensive care coordination and related community-based services to serve these children.

4. Critical Services for Expansion

Many of the critical in-home and community-based services that will support children in the community are already in place in West Virginia, though they are not currently accessible to all children who need them, in sufficient quantity, or in all parts of the State. A sufficient array of in-home and community-based services incorporates several discrete clinical interventions, including, at a minimum:

- Intensive care coordination, e.g., Wraparound with fidelity to the National Wraparound Initiative standards;
- In-home and community-based direct services of sufficient frequency, intensity, comprehensiveness and duration to address the youth and family's needs (e.g., strength-based assessments, clinical teams, individualized treatment interventions such as specialized behavior supports, therapeutic mentoring, in-home individual and family treatment and parent coaching, school-based mental health services, intensive outpatient services, interventions such as those provided by ACT teams, respite);
- Responsive and individualized crisis response and stabilization services available 24 hours a day, 7 days a week, including immediate access to back-up crisis stabilization when actually needed so a youth can spend the majority of his/her time living in a more integrated community setting; and
- Therapeutic Foster Care, which as noted above, is an intensive, individualized mental health service provided in a family setting, using specially trained and intensively supervised foster parents.

To be effective, the treatment must be provided in a flexible manner with sufficient duration, intensity, comprehensiveness, and frequency to address the child's mental health needs. There is no "one size fits all" approach when providing mental health services and supports. It is therefore essential that a diverse array of services exist to meet the unique needs of each child and family and allow a child and family team to develop an individualized treatment plan. That team should consist of the child's family (including the child or youth), relevant service providers, and others such as teachers, coaches, neighbors, and extended family members. An accountable case manager should provide coordination of services.

Successful community service systems integrate core principles in their system of care:

- Comprehensive service delivery, incorporating a broad array of services and supports, including integration of clinical treatment services and natural supports, and linkage to community resources;
- Individualized services/supports “wrapped around” the child and family with the frequency, intensity and duration necessary to address the child’s needs;
- Services provided in the least restrictive, most integrated setting;
- Coordinated and integrated services across agencies and monitoring with one accountable case manager guiding a single treatment plan;
- Coordination across agencies at both the system and service delivery levels;
- Involvement of families and youth as full partners;
- Coordinated financing across child-serving agencies; and
- An organized, accessible pathway to services and supports.

West Virginia’s service array includes services that the State could expand to support children with significant mental health needs in the community. Some of these services include Basic Living Skills Development, Assertive Community Treatment and Targeted Case Management in the Medicaid State Plan, pilot projects such as the Therapeutic Foster Care project, in-home and community-based services provided through a joint effort by a provider and community organization , and intensive in-home and community-based services provided in pockets of the State as a result of provider initiative.

DHHR also purports to cover non-clinical services (referred to as Socially Necessary Services) such as Mentoring, Intensive Family Preservation, and Respite for children in the child welfare system. Mental health providers across the state are largely unwilling to provide these services, citing high denial rates for authorization, underfunding, or high staff credentialing among the barriers. Nonetheless, these services exist, and the State could integrate them into its mental health system and further develop them to support children with significant mental health needs in their homes and communities. Similarly, the recent approval of the State’s IV-E Waiver allows for greater flexibility in child welfare service delivery, including the potential for wraparound and community-based services for children involved with the child welfare system.

States that have successfully developed integrated mental health services have done so by fostering engagement of families and community members as full partners in developing strategies to support children in their homes and communities. DHHR has long recognized the significant need for, and lack of, child and family outreach and engagement. Families do not feel welcomed, supported and heard by service agency staff. Family participation can improve the way DHHR serves children and adults by increasing DHHR’s focus on families, the provision of services in natural settings, and cultural sensitivity, all of which foster an effective community-based system of care. Collaboration with schools and other naturally existing community supports, including the faith community, civic organizations, and the business community, is also essential.

5. West Virginia Has a Provider Base Experienced in Providing In-home and Community-based Mental Health Services

West Virginia is also fortunate to have DHHR-contracted providers with the requisite expertise needed to support children in their home communities. Programs in West Virginia have had success with home- and community-based Individual Counseling and Therapeutic Behavioral Supports and Therapeutic Foster Care for Medicaid-eligible youth with significant mental health needs. These successes could be replicated across the state. One provider of in-home and community-based services with demonstrated success in other states has relatively recently begun to provide Individual Counseling and Therapeutic Behavioral Supports in home and community-based settings for Medicaid children with significant needs. It reports that its average monthly rate for Medicaid funded in-home and community-based services is \$2,500 per child. Staff generally provide services eight hours per week in the family's home, which allows for applying the wraparound model with individual counseling. The counselor develops a behavioral support plan to teach the family how to address targeted behavior problems in the home. An additional counselor may provide support in the home in implementing the plan. The approach involves working with both the parent and the child and usually lasts for six months.

Another example of an existing West Virginia community-based service for children with intensive mental health needs is the Therapeutic Foster Care pilot program. The provider operating the pilot has successfully run a similar program in a neighboring state. To date, the State has referred only a few children to the program, and they have been primarily children with needs other than mental health support. However, this pilot program brings expertise and experience to the state that can be a resource for further development of Therapeutic Foster Care for children with significant mental health needs.

In addition, other resources are available within the state to develop provider capacity, including individuals involved in the West Virginia Systems of Care project and the Mountain State Family Alliance. West Virginia previously operated Mountain State Family Alliance's wraparound services with in-home and community-based mental health services in twelve Southwestern counties under a SAMHSA System of Care Grant. When this grant ended in 2007, the State did not incorporate the services into the State's mental health system. Nonetheless, administrators, providers, and families in the community have direct experience with providing integrated services that could further assist the State in transitioning away from a segregated system dependent on residential treatment facilities. Each of these West Virginia programs could provide valuable insight into how to support children in their homes and communities, and could serve as a model for the further development of expertise within the state.

V. ADDITIONAL BARRIERS TO SERVING CHILDREN WITH MENTAL HEALTH ISSUES IN THE MOST INTEGRATED SETTING

Throughout our investigation, we identified additional barriers that affect West Virginia's compliance with the ADA. These areas include the provision of appropriate special education and related services to children with mental health conditions, the State's response to truancy, consideration of the most integrated setting by Juvenile Court judges, and barriers to children accessing Medicaid Early Periodic, Screening, Diagnostic, and Treatment services. Because

these areas are outside the scope of our investigation, we have made no findings regarding them. However, we recommend that the State examine these areas and consider how it could improve its system of care for children with mental health conditions.

A. Implementation of the Individuals with Disabilities Education Act (“IDEA”)

Across the state, we learned that school-related incidents are frequently what led to children with mental health conditions being charged with status or delinquency offenses, and ultimately to placement in segregated residential treatment facilities or juvenile detention centers. In West Virginia, children with disabilities who require special education services are over represented among students referred to law enforcement, subjected to school related arrests, and suspended and expelled. During the 2009-2010 school year, children with disabilities represented 17% of the overall West Virginia student population. However, they represent a much higher number of the children punished for school misconduct. Students with disabilities represented 34% of school related arrests and 22% of referrals to law enforcement. Children with disabilities also represented 26% of students suspended out of school more than once and 27% of students expelled under zero tolerance policies.

Children with covered disabilities are entitled to a “free appropriate public education” in the “least restrictive environment” including the provision of related services and supplementary aids and services. 20 U.S.C. § 1400(d)(1)(A) (2004); *see also* 20 U.S.C. § 1400(c)(3) and 1412(a)(5). Related services include supportive services such as social work services, counseling, and medical diagnostic and evaluation services. 20 U.S.C. § 1401 (26). Supplementary aids and services are supports provided to enable the child to be educated with non-disabled children. *Id.* § 1401 (33).

Children with mental health conditions and their families reported to us that schools denied related services and supplementary aids they needed to receive a free appropriate public education in the least restrictive environment. In addition, families reported that school staff would often fail to implement the child’s Individual Education Program when specific interventions were required to support the child at school. School districts reportedly would claim that the services needed to support the child were too expensive for the school to provide. Because the children did not receive these services, behavioral problems went unaddressed, the schools suspended the children and suspension and truancy were the first steps in a path that led to placement in segregated residential treatment facilities.

These allegations implicate the State’s compliance with the IDEA. We believe the State would benefit from reviewing school district compliance with the obligations of the IDEA as part of its analysis of the system of care for children. The State should consider whether training for school district IEP teams, and support for the further expansion of School Based Mental Health programs across the state are appropriate.

B. West Virginia’s Response to Truancy

Increased prosecution of status offenses, specifically truancy, has caused the State to place many of its children with mental health conditions in segregated residential treatment facilities. Based on 2012 data from the West Virginia Intergovernmental Task Force on Juvenile

Justice, 51% of the juvenile justice-involved children in DHHR custody placed in segregated residential treatment facilities were status offenders. Additionally, placements of status offenders in segregated residential treatment facilities have increased by 255% since 2002. Attorneys and providers informed us that the State's recent emphasis on prosecuting truancy is largely the reason for this increase in prosecution of children with mental health conditions for low-level status offenses. Judges, prosecutors and defense attorneys told us that truancy cases dominate the juvenile docket; one Public Defender said that, at one point in 2014, he had 110 open cases and 99 of them were truancy prosecutions.

West Virginia law and policy has allowed school districts to initiate court proceedings after a child misses five unexcused days in a school year. *See* W. Va. Code §18-8-4(b); W. Va. Bd. Of Educ. Legis. R. 126 CSR 81 (2010); *see also* W. Va. Code § 49-1-4(15)(c). During this most recent legislative session, West Virginia changed the number of unexcused absences that trigger a truancy petition from five to ten. H.B. 2550, 2015 Leg. (W. Va. 2015). While this change will likely decrease the number of children adjudicated as truant, there remain issues in how the State addresses the possible link between truancy and mental health conditions.

From our interviews with children and families, it appears that part of the reason such large numbers of children with mental health conditions are adjudicated as truant may be a failure to consider whether truancy issues are a manifestation of a child's disability.⁸ One of the school-based mental health pilot program providers reported to us that it has attempted to teach school personnel to recognize habitual truancy as a sign of possible mental health concerns, and to refer those cases first to the provider, rather than to the courts. This approach, according to the provider, has led to a decrease in truancy prosecutions in the schools where they provide services. West Virginia should consider whether implementing additional community or school-based mental health interventions to address truancy is appropriate.

C. Court Imposed Improvement Periods and the Abilities of Children with Mental Health Conditions

As discussed above, West Virginia Courts' improvement period conditions, according to our informants and documents we reviewed, currently do not require DHHR to provide sufficient assistance to children with disabilities so that they can comply with the terms. While the conditions imposed during improvement periods are supposed to serve the rehabilitative needs of the child, children with mental health conditions, their families, attorneys, and advocates expressed concern about the feasibility of some of the conditions imposed when a child is on an improvement period without needed community-based mental health services. The conditions are often not individualized and do not consider the child's mental health condition. Once a child violates one of the terms, he or she faces additional consequences, including potential placement in a segregated residential treatment facility.

⁸ To the extent that initiating truancy proceedings constitutes a long-term disciplinary removal or a change of educational placement for disciplinary reasons, it is important to note that a manifestation determination is required as part of a free appropriate public education under both the IDEA and the Department of Education's interpretations of its Section 504 regulations. *See* 34 C.F.R. §§ 300.530(e) and 104.35. However, these provisions do not prohibit the reporting of a crime to the appropriate authorities. *See* 34 C.F.R. § 300.535.

The information we reviewed suggests that judges do not adjust the terms of improvement periods to accommodate the ability of children with mental health conditions to comply with the terms. The children with mental health conditions, because of their disability and histories of trauma, often present challenges to the service systems responsible for addressing those needs. A child with a mental health condition needing services and supports that have not been provided is much less able to satisfy the order's terms – such as not interrupting the educational process – than a typical child is. Without accommodations, these improvement period orders may be setting up children with disabilities to fail.

It is our recommendation that West Virginia examine the current improvement period process to determine if children with mental health conditions are disadvantaged by the terms imposed, and if so, assess how those children may be adequately supported with the services necessary to be successful.

D. Access to Needed Medicaid Services

Numerous sources identified significant, and at times insurmountable, barriers to accessing Medicaid funded mental health services and supports for children with mental health conditions. As discussed more fully above, the Medicaid Early, Periodic Screening, Diagnostic and Treatment (EPSDT) service requires participating states to provide for all Medicaid-coverable services necessary to correct or ameliorate a child's mental health condition up to the age of twenty-one. 42 U.S.C. § 1396d(a)(4)(B). We believe that the State would benefit from reviewing its compliance with its EPSDT obligations as part of any remedial efforts.

VI. RECOMMENDED REMEDIAL MEASURES

To remedy its failure to serve children and youth with mental health conditions in the most integrated setting appropriate to their needs, consistent with the mandate of Title II of the ADA and its implementing regulations, the State should promptly implement the minimum remedial measures set forth below:

- West Virginia should expand in-home and community-based mental health service capacity throughout the state to minimize or eliminate unnecessary institutionalization, prolonged institutionalization, and heightened risk for institutionalization, and to reduce the risk youth with disabilities will end up in settings that are not designed to provide mental health care, such as detention centers, correctional facilities, and jails. West Virginia should provide quality oversight and public accountability for all in-home and community-based mental health services.
- West Virginia should eliminate the unnecessary use of public and private segregated residential treatment facilities, both within the state and outside of the state. The State should ensure the availability of voluntary, comprehensive services and supports in the community to divert children from segregated residential placement. West Virginia should provide quality oversight and public accountability for all segregated residential treatment facilities.

- West Virginia should ensure that all Comprehensive Centers provide for (directly or indirectly) in-home and community-based mental health services across the state including Intensive Care Coordination, Crisis Response and Stabilization, In-home and Community-based Direct Services and Therapeutic Foster Care. The State should deliver these services with fidelity to national models and appropriate evidence based criteria. In addition, flexible services and supports should be available in sufficient amount, duration, and scope to all children who need them to be successful in the community, including respite, transportation, and family/peer support. West Virginia should provide quality oversight and public accountability for all children's mental health services provided by or through the Comprehensive Centers.
- West Virginia policy, practice, and regulations should ensure that a single Intensive Care Coordinator has ultimate responsibility and accountability in cases where a child is involved in multiple child-serving systems (such as child welfare, juvenile justice, Medicaid, and special education). The State should charge this Intensive Care Coordinator with ensuring the planning, delivery and monitoring of services and supports consistent with State and federal law. This entity should coordinate the provision of services using a high fidelity Wraparound model pursuant to the National Wraparound Initiative's published guidance.
- West Virginia should develop an interagency decision making and oversight entity to improve coordination of and access to intensive mental health services. The entity should have authority, inform decision making, and be accountable. The entity should include sufficient membership and participation by families, youth, and advocates to meaningfully inform and provide oversight of high-level policy development, program planning, decision making, and implementation of remedial actions stemming from this letter.
- West Virginia should modify its policies and practices to ensure the effective engagement of families as full partners in the assessment, planning, and implementation of services and supports to children with significant mental health needs, both at the individual child level as well as in the development strategies to support children in their homes and communities across the state.
- West Virginia should provide families, children and youth with accurate, timely, and accessible information regarding the services available in their communities that can meet the needs of the individual child and his or her family in the most integrated setting.
- West Virginia should develop and implement a cross-system remedial plan that ensures children and youth throughout the state, including children eligible for Medicaid, involved in the mental health, child welfare, juvenile justice and/or educational systems are not unnecessarily placed in segregated residential treatment facilities. This remedial plan should include outreach and educational

programs for stakeholders including judges and other court personnel, law enforcement, educational personnel and others. It should specifically address the heightened risk factors experienced by status offenders with mental illness, older children and youth, children and youth with mental health and intellectual disabilities, LGBTQ children and youth, trauma exposed children, minority children, and children with prior placement histories.

- West Virginia should assess each individual placed in segregated residential treatment facilities by DHHR or through funding from DHHR, based on the principle that with appropriate supports and services, the State can serve individuals in an integrated community setting. All assessments should include an individualized analysis of the services and supports needed to ensure success in their homes, or alternative homes, and in the community. Assessments of children and youth who have histories of multiple admissions to segregated residential treatment facilities should consider and address the factors that have led to readmissions and multiple placements. West Virginia should modify its policies and practices to ensure that children and youth are not retained in segregated residential placements for longer than is necessary to stabilize the individual and provide services that address the immediate need for placement.

VII. CONCLUSION

This letter is a public document, which the Department of Justice will post on its website. We hope that you will give this letter careful consideration and that it will assist in facilitating the development and implementation of remedial measures to address outstanding issues of concern. We hope to engage the State in the coming weeks in an in-depth dialogue about the remedies needed in the context of structured negotiations. Ultimately, we hope to be able to reach an agreement with the State on a written, enforceable settlement agreement that would set forth the remedial actions that the State will take within a specified period to address each area of concern.

We are obligated to inform you that if the State declines to enter into voluntary compliance negotiations or if our negotiations are unsuccessful, the United States may take appropriate action, including initiating a lawsuit, to ensure the State's compliance with the ADA. We would prefer, however, to resolve this matter by working cooperatively with the State. We are encouraged by our positive interactions thus far with State leadership, and hope there is a desire to work with the United States toward an amicable resolution.

Thank you for your ongoing cooperation in this matter. We will contact you soon to discuss the issues referenced in this letter and to set a date and time to meet in person to discuss a remedial framework in which to address any outstanding individual and systemic concerns. If you have any questions, please feel free to contact Judith C. Preston, Acting Chief of the

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Civil Rights Division's Special Litigation Section, at (202) 514-6258, or Regan Bailey, the lead attorney assigned to this matter, at Regan.Bailey@usdoj.gov or (202) 305-3113.

Sincerely,



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